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Fragmented Management of Long-Term Parenteral Support for Adult Intestinal Failure in Finland

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AP, MP, and TS devised the study protocol, collected the data, analysed the results, drafted the manuscript, and approved the final version for submission.

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Objectives: Parenteral support (PS) is the first-line therapy for intestinal failure (IF). Optimal patient outcomes require experienced multidisciplinary teams adhering to structured protocols. As practices to provide long-term PS for adult IF patients in Finland are unknown, this cross-sectional nationwide study aimed to evaluate current management of PS for adult IF across the country.

Materials and Methods: An internet-based survey was emailed to all Finnish hospitals and hospital-at-home services with the potential to provide PS for adult IF. The survey included 20 items addressing provision of long-term PS for adult IF patients (aged ≥18 years). Data were analysed using descriptive statistics.

Results: Overall**,** 52 (47%) of the 111 identified units responded. Of responding units, 38 (73%) had at some point provided long-term (≥120 days) PS for adult IF, and 23 (44%) had done so during the preceding year. Only three units currently managed ≥3 adult patients. Most (65%) of the respondents worked in a hospital and were either physicians (38%) or dietitians (39%). Only 65% of respondents reported that their unit had an assigned physician responsible for PS provision, and 28% reported that a team was responsible for long-term PS. Only 26% of respondents reported having a written protocol to guide PS management.

Conclusions: Health care providers with very limited experience and a fragmented approach manage most Finnish adult IF patients. Evidence-based protocols and multidisciplinary teams are scarce. The care for adult IF patients on long-term PS needs to be improved in Finland.

Keywords: parenteral support; intravenous supplementation; home parenteral nutrition; intestinal failure; short bowel syndrome

Introduction

Intestinal failure (IF) is a rare disease defined as a reduction in gut function leading to an inability to maintain health unless parenteral support (PS) is provided [1]. In addition to long-term PS consisting of nutrition and/or fluid and electrolytes, patients require individually tailored medical and nutritional treatment and, in many cases, surgery [2]. To achieve optimal outcomes, specialized teams and structured protocols in managing IF seem to have a key role [3, 4, 5, 6].

Comprehensive reviews of the management of short bowel syndrome, the most common cause of IF, can be found in the literature [7, 8, 9]. More recently, an extensive guideline covering the whole spectrum of IF in adult patients has been published [2]. Guidelines are well adhered to and management strategies for nutritional care in paediatric patients are relatively consistent among specialized centres [10, 11]. The introduction of multidisciplinary intestinal rehabilitation programmes has resulted in improved clinical outcomes of IF, especially in paediatric patient populations [3, 4, 5, 6]. Intestinal rehabilitation programmes require experienced staff before having an impact on outcomes such as patient survival [4, 6, 12].

The need for long-term PS, commonly referred to as home parenteral nutrition (HPN), is often used as a synonym for IF. However, these two terms, IF and HPN, do not necessarily refer to the same patient population. Long-term PS can also be used in some less well-defined conditions, where the gut function is not truly compromised [13], e.g. anorexia in cancer cachexia.

To the best of our knowledge, the clinical practices for long-term PS have not previously been investigated among adult IF patients in Finland. The aim of this cross-sectional study was to evaluate current management of long-term PS for adult IF patients across the country.

Materials and Methods

Study Protocol

An email with a cover letter and a link to an electronic survey was sent to chief physicians of the departments of gastroenterology, gastrointestinal surgery, anaesthesiology, and internal medicine, to clinical dietitians working in all Finnish hospitals, and to chief physicians or head nurses of all public and private hospital-at-home services across Finland. A reminder was sent two weeks later.

Data Collection

The electronic survey included 19 questions regarding the local practices of long-term PS. These were structured multiple-choice questions, but the respondents were able to write free text in comment boxes if they wanted to expand their answers. In addition, the participants were asked whether their unit had provided PS to any patient(s) aged ≥18 years for at least 120 consecutive days during the preceding 12 months.

Statistical Analysis

The descriptive data are presented as frequencies and percentages. The IBM SPSS software package (version 24) was used for the analyses.

Ethics Statement

The study was approved by the Medical Research Ethics Committee of Helsinki University Hospital (HUS/751/2017).

Results

Participation Rate and Respondents

An electronic survey was emailed to 306 health care professionals working in 111 separate units identified across Finland. In total, 71 individuals representing 52 different health care providers responded, resulting in an overall response rate of 47% for the units (Table 1). The majority of respondents worked in a hospital and were either physicians or dietitians (Table 2). Responses were obtained from all Finnish hospital districts.

Experience in Patients with Long-Term PS in Finnish Health Care Units

Altogether 28 survey respondents (39%) reported that, to their knowledge, their unit had never treated an adult patient receiving PS for 120 days. These respondents were not asked questions concerning long-term PS. This left 43 participants from 38 units to answer the survey questions pertaining to management of long-term PS in their unit. Twenty-three different units were treating or had treated at least one patient with long-term PS during the preceding year. Only three units (13%) were currently treating three or more adult patients. Therefore, the great majority of the responding units managed currently only one or two patients with long-term PS.

Management of Long-Term PS

The majority of the respondents (65%) reported their patients to have an assigned physician responsible for provision of PS (Table 3). However, it was uncommon to have an assigned nurse or a team responsible for the management of patients on long-term PS (Table 3). Most of the respondents who reported having an assigned management team were working in a hospital-at-home service (8 out of 12 respondents). The remaining four respondents worked in a university hospital.

The most frequently mentioned members of the team were a nurse (10 responses), a physician (usually a specialist in general practice) working in the hospital-at-home service (6 responses), a gastroenterologist or specialist in internal medicine (5 responses), and a dietitian (4 responses). No unit had a psychologist or a social worker as an assigned member of the team.

Every third respondent reported that PS is not based on any recommendation or guideline in their unit, or the respondent did not know whether it is (Table 3). When a guideline was used, it was a national or international guideline in 37% and a local guideline in 63% of the units. Most of the respondents reported not having a written protocol on the management of IVS in practice (Table 3).

Nine respondents reported that they have or have had patients who were compelled to stay admitted in hospital because practical issues prevented the administration of PS at home, even though the health status of the patient would otherwise have allowed the patient to be discharged.

Respondents working in a hospital-at-home service frequently reported carrying out a PS plan created by another unit (Table 4). Otherwise, no uniform pattern was found in the planning of PS. In their comments, the respondents often described that several specialists devise the plan together and/or with the help of a consulting specialist.

Less than half of the respondents reported teaching the patient how to administer parenteral infusions independently (Table 3). If the administration of infusions was taught, typically a nurse was responsible for the instruction (18 responses out of 19). Nurses were most frequently (33 responses) responsible for supplementing (e.g. additional vitamins or electrolytes) the PS bags. Only six respondents reported that patients or their relatives did this themselves.

Great variation was observed in responses to questions about who is responsible for the practical administration of PS and how patients are supplied the PS products or the equipment

for the administration (Tables 5 and 6). Hospital-at-home service was most frequently mentioned to deal with the practical administration of PS as well as to supply the patient with parenteral products and equipment.

Only 36% of the respondents reported routine use of infusion pumps for the administration of PS (Table 7). Approximately half of the respondents stated that infusion pump and infusion stand were possible to arrange for the patient (Table 6). Only 12 respondents reported the possibility to provide the patient with a portable infusion pump.

Discussion

Our results suggest that organized multidisciplinary team work and treatment protocols are rare in the context of adult IF and long-term PS in Finnish health care units. Most of the units manage only one or two adults with long-term PS. This study is the first step towards enhancing our understanding of the management of IF in the Finnish adult population.

The prevalence of IF seems to be increasing in the Western countries [14, 15, 16], and it is likely that a similar development will also occur in Finland. The underlying reasons for the increase may include e.g. the good overall survival rates [17, 18]. Our findings are helpful in organizing management of adult IF in Finnish health care units. The urgent need for standardized management protocols and implementation of evidence-based guidelines as well as multidisciplinary care was clearly revealed in this survey.

Management of paediatric IF in Finland has been centralized for many years, enabling continuous development of the programme, and consequently, high-quality outcomes [5, 19]. Furthermore, a Finnish national programme for intestinal transplantation (ITx) has been ongoing since 2009. Therefore, it is surprising to note that, unlike in other benign chronic

diseases, such as renal failure, management of IF in adults lacks nationwide organization in Finland.

In the Nordic countries, Denmark has the longest tradition in managing IF patients [20], and the prevalence of IF in Denmark is among the highest in Europe [14]. The first Danish patient started HPN already in 1970, and nowadays, the largest Danish referral IF centre has over 150 patients in their well-structured HPN programme [21]. Attempts of nationwide organization of adult IF care have also taken place in other Nordic countries. Sahlgrenska University Hospital in Gothenburg, Sweden, provides surgical treatment of IF, and the unit has experience with ITx since 1998 [22]. An initiative to launch a national registry for short bowel syndrome in Sweden was described already in 2004 [23]. In Norway, the Oslo University Hospital serves as a national referral centre for Norwegian IF patients who are candidates for ITx [24].

Long-term PS can be provided effectively and safely outside the designated IF units [25, 26]. This will become increasingly necessary as the volume of patients grows. However, as recent evidence shows [3, 4, 5, 6], optimal patient outcomes in IF cannot be expected in the absence of the required experience and skills of staff and a standardized protocol.

To fulfil the above-mentioned requirements, the management of adult IF needs to be concentrated in Finland. The concept of centralized care of rare diseases with complex treatment is strongly supported by European and Finnish health care authorities. Active co-operation between the national referral centre and smaller units across the country is essential. Telehealth services might be one means of facilitating this co-operation. Telehealth enables regular face-to-face contacts with experts of the specialist IF centre without the burden and cost of long-distance travelling [27], which are real concerns for patients living in the sparsely populated northern part of Finland.

Apart from the care given by health care professionals and the technical solutions, peer support and education by patient organizations are also important factors affecting the well-being of patients on long-term PS. A previous case-control study among North American patients receiving HPN suggested that a connection with a national patient organization has a positive effect on clinically important patient outcomes such as quality of life, depression scores, and incidence of catheter-related infections [28]. In Finland, a patient organization for IF is lacking, representing another approach to improve overall outcomes.

Even though this study was limited by the relatively low overall response rate, the geographical coverage of the survey was comprehensive. In addition, over 80% of the university and central hospitals, where the majority of the patients are treated, responded. Less than two-thirds of the respondents had any experience with patients with long-term PS. We speculate that smaller units (i.e. regional hospitals and hospital-at-home services from smaller towns) without any experience with adult IF were less likely to respond. Therefore, our results should reflect clinical reality with reasonable accuracy. Most survey questions covered the practices in the respondent's unit. Individual respondents might have interpreted the concept of a unit in different ways (e.g. as the whole hospital or as a specific unit within the hospital). Therefore, we decided to report the results from single respondents as opposed to units. In addition, the results showed that even professionals working in the same hospital could give different answers. This can be regarded as a consequence of the lack of uniform practices, which indeed was one of the main results of this study.

We are currently in the process of investigating the prevalence of Finnish adult IF, the characteristics of the affected population, and the details of their care **(e.g. incidence of catheter-related bloodstream infections),** which were not objectives of this study. On a national level, there is an urgent need for improved care of Finnish adult IF patients requiring long-term PS. The first steps towards this should include devising a national recommendation

on management of adult IF in Finnish language, creating a network of units managing this patient group and coordination of care by a national referral centre.

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Disclosure of Interest

The authors report no conflict of interest.

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Figure and Table Legends

Table 1. Response rate of the identified units according to the type of health care provider.

	Invited, *n*	Participated, *n* (%)
University hospital	11	10 (91)
Central hospital	15	11 (73)
Regional hospital	15	7 (47)
Hospital-at-home service	69	23 (33)
Other	1	1 (100)
Total	111	52 (47)

Table 2. Demographic data on respondents (n = 71).

		n (%)
Profession	Physician	27 (38)
	Dietitian	28 (39)
	Nurse	16 (23)
Place of employment	Hospital	46 (65)
	Hospital-at-home service	24 (34)
	Other	1 (1)
Type of hospital for those working in hospital (n = 46)	University hospital	18 (39)
	Central hospital	22 (48)
	Regional hospital	6 (13)

Table 3. Management of long-term parenteral support (PS) (n = 43).

	Yes	No	I don't know	Missing
The patient has an assigned physician in the unit responsible for PS	28 (65%)	12 (28%)	3 (7%)	-
The patient has an assigned nurse in the unit responsible for PS	7 (16%)	29 (68%)	7 (16%)	-
In the unit, an assigned team is responsible for the management of patients on PS	12 (28%)	30 (70%)	1 (2%)	-
The patient is taught how to independently manage his/her PS by the staff in the unit	19 (44%)	18 (42%)	6 (14%)	-
The PS provided by the unit is based on a recommendation or guideline	24 (63%)	6 (16%)	8 (21%)	5
The unit has a written protocol and/or guideline on the management of PS in practice	10 (26%)	25 (64%)	4 (10%)	4

Table 4. Person(s) in charge for the plan of parenteral support (multiple choices possible).

	Number of responses	
	Hospital	Hospital-at-home service
Anaesthesiologist	6	0
Specialist in internal medicine	1	0
Gastroenterologist	1	0
Surgeon	1	0
Dietitian	8	0
The unit carries out a plan devised in another unit	0	12
I don't know	2	0
Someone else	6	6

Table 5. Unit responsible for administration of parenteral support in practice (multiple choices possible).

	Number of responses
Hospital-at-home service	36
Hospital	15
Health centre	6
Patient him-/herself	6
I don't know	1
Some other unit	3

Table 6. Supply of parenteral products and equipment needed for parenteral support (PS; multiple choices possible).

		Number of responses
The patient gets his/her parenteral products from	Hospital-at-home service	32
	Hospital	12
	Health centre	8
	Pharmacy	5
	I don't know	5
	Somewhere else	3
The patient gets PS equipment from	Hospital-at-home service	29
	Hospital	8
	Health centre	7
	Public health care distribution of self-treatment products	8
	I don't know	6
	Somewhere else	0
Our unit provides the following equipment for PS	Infusion pump	21
	Infusion stand	27
	Portable infusion pump	12
	None of these	4

Table 7. Use of an infusion pump for parenteral nutrition (n = 43).

	n (%)
Always	14 (36)
Often	5 (13)
Seldom	7 (18)
Never	8 (20)
I don't know	5 (13)
Missing	4